



# Toronto Anaphylaxis Education Group

MEETING NOTES - Tuesday, October 9, 2012

TOPIC: Safe & Inclusive Schools

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## Meeting introduction and icebreaker

TAEG President Sarah Nicholl welcomed everyone, described the purpose of TAEG, asked how many people had been to a TAEG meeting before (approx. 50% had, 50% were new). Sarah set out the meeting agenda.

In order to get to know each other better, attendees were asked to introduce themselves to the person sitting next to them and describe how they discovered that they/ their child had food allergies.

## Safe School Panel Discussion

### Panel Participants:

- Principal, Public School (JK-grade 5)
- Principal, Montessori School (JK – grade 3)
- Parent of an allergic teenage boy
- Parent of allergic teenage girl panellist
- Teenage girl with allergies

## Panel Questions

### How do you foster an inclusive school environment?

#### PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5) :

- Begins with education. Make sure every teacher (including gym teacher) is trained to use an EpiPen. Teach parents that they have to ask questions about food & ingredients that they are sending to school. Include information in school assemblies.
- Things evolve with time & knowledge. Before, used to have kids eat snacks outside, weather permitting. Realized it attracts bees, which some kids are allergic to, so moved snacks inside. Now, teacher can monitor snacks to make sure they are “nut free”. Teachers & other kids will notice if a snack isn’t nut free – now they send it home with a note to parents that they cannot send this particular snack.
- Kids are very accepting and very aware of food allergies. They support their classmates who have allergies.
- Keep pictures of children with allergies in school office so all staff is aware, not just their teacher. Note if they wear their epipens. She prefers if kids wear epipens, so that time is not lost getting one in case of an emergency.
- Policy of no birthday treats is sometimes difficult for parents to understand. If there are treats sent in that are not safe, they are not distributed, they get sent home.
- Make sure supply teachers know about children with allergies.

- Has found that kids are best advocates for one another. The kids with allergies don't feel excluded.

**PARENT OF AN ALLERGIC TEENAGE BOY:**

- Parents have to figure out how to work with school to plan for their child's entry into school.
- When her son was young, before allergy awareness and "nut free" policies, she did all the baking to ensure things were safe for him. She would always attend parties to supervise him, but he was compliant, he would only eat the things that she made.
- Prior to her middle son's diagnosis with peanut allergy, her older (non-allergic) son had a classmate with a peanut allergy, and he decided on his own to not bring anything with peanuts to school. Even young children can be empathetic.
- Parent of an allergic teenage boy always sent lots of treats to birthday parties, so that her allergic son could share with others.
- Until grade 9, he wore his EpiPen on his belt. Now that he's in grade 10, he puts it in his backpack – not as safe b/c may not have backpack with him at all times, but still takes it most places with him. Harder on weekends when he doesn't carry his backpack.
- She made sure his friends' parents & coaches know about his allergies. She trains them how to use an EpiPen before he stayed over, went to cottage, went on team trips, etc.
- As he gets older, she has discussions with her son about safe choices. Now he is starting to take risks – for example, goes to Tim Horton's with friends and has a coffee.
- Complexity must be greater with multiple allergies.

**PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:**

- School is nut free.
- School has boxes with EpiPens around, but no one checks regularly, some have expired.
- School rule is that every child with food allergy must wear their EpiPen.
- Class celebrations are very strict, can bring in food, but must be packaged & nut-free. It's harder with allergies to things other than nuts. Knows of a child with dairy allergy whose family removes him from school once a month on "pizza day".
- Has found that kids are good advocates; they tell their parents they can't bring things if others are allergic.
- Start teaching kids about allergies when they are young; when they are older, it's just natural.

**PRINCIPAL, MONTESSORI SCHOOL (JK – GRADE 3):**

- Principal at a small school, so everyone knows the allergic kids & their allergies.
- Snacks are very limited: mostly fruits & vegetables.
- In the Casa program (Pre-school-grade 1) very safe environment, teachers clean w/ disposable wipes twice daily.

- Have posters describing symptoms of allergic reactions, not just obvious ones. Call parents if they have any doubts.
- Kids are very good at following rules, they will remind parents of rules (e.g. her own son reminded her when packing his school lunch that she must leave outer packaging on so they can read ingredients).
- If they have doubts about any food that was sent with child, they send it home and contact the parents.
- With young children, teacher must monitor food intake and be very experienced. At older age, kids monitor as well.

## What would you advise other kids who are starting school?

### TEENAGE GIRL WITH ALLERGIES (teen with food allergies):

- Have EpiPen at all times; unlikely to have reaction if careful, but it can save your life.
- When kids are young, parents advise/ educate teachers about allergies, as the kids get older, the student takes responsibility.
- Don't exclude self from social situations – get parents involved to help with planning, bring own snacks.
- Wear medic-alert bracelet

### PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:

- When her daughter was younger, she distributed a list of safe snacks to other parents.

## What safety plans are put in place when an allergic child starts school?

### PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5):

- The most important thing a parent can do is make an appointment with the principal to discuss the child's needs and make a plan. Parents need to take the initiative to educate the school about their particular child's needs. Discuss the issues for your child, even if there are other children in the school with similar allergies. Every teacher that teaches that child has to be educated about allergies (e.g. gym teacher, French teacher, etc.). ALWAYS tell the school.

### PRINCIPAL, MONTESSORI SCHOOL (JK – GRADE 3):

- Parents should always take the initiative and communicate.
- Had a student in her class in mid-90s, parent never told her that the child had a peanut allergy. It was only when she saw the parent in a non-school setting that the parent mentioned the child had had a minor allergic reaction (rash) to peanuts he had encountered at a school party. She was shocked.
- Don't downplay allergies. Parents don't want to be pushy or obnoxious, but parents must take charge to keep their children safe. Better to overplay.

## What strategies have worked with schools in your experience?

### PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:

- The school thought that their “nut free” policy was all they needed from allergy perspective; but there are other allergies (like her daughter’s mustard allergy) that are not addressed by that policy.
- Her school has a “hot dog day” – got the school to agree that there would be no mustard served with the hot dogs in her daughter’s class room. There was some negative reaction (“my kid likes mustard on his hot dog”), but the policy stood. Unfortunately, the hot dogs they serve have mustard as an ingredient, so still not safe for her daughter. The solution was for her daughter to sit in the hall to eat her lunch, but she is allowed to take a friend with her to eat their lunches in the hall.

## How did sitting in the hall while your classmates ate hot dogs in the class make you feel?

### TEENAGE GIRL WITH ALLERGIES:

- I understood it was for my own safety. It was ok when a friend would come sit with me, but sometimes the friend would choose to stay in the class with everyone else rather than go out & sit with me. Then she was upset to sit alone.
- Now that she’s older, there is a longer lunch period, so there is enough time for her friends to eat, wash their hands & come sit with her.

(returning to earlier question)

## What strategies have worked with schools in your experience?

### PARENT OF AN ALLERGIC TEENAGE BOY:

- When her son was first diagnosed, peanut allergies were not very common. Some child care providers told her that they could not handle a peanut/ tree nut allergy.
- Every year, she would meet with the teachers & the day care workers to educate them about his peanut allergy. Some people were very dismissive, as though they didn’t believe the severity; others felt that they knew everything already.
- It’s still hard now that he is older. He travels to go to hockey tournaments and they have to leave restaurants b/c there is nothing for him to eat. He does sometimes feel excluded – not being able to order off a menu, not being able to try delicious-looking desserts that his friends are having, always eating the homemade treat. There always seem to be Timbits at hockey games, which he can never have.
- One good thing about having a food allergy in the family: when her sons were younger, her older (non-allergic) son recognized another child having an allergic reaction on a playground. He told the playground supervisor about the reaction and where the Epi pens were located in the school.

- More allergies would require more vigilance.

## OPEN QUESTIONS from members:

### Can you suggest any concrete strategies for non-nut allergies?

**PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:** teach kids early: what they are allergic to, what foods they have to bring, to wash hands before eating, to clean desks/ tables. Start when they are young.

**TEENAGE GIRL WITH ALLERGIES:** teach kids about the exposure and severity of reactions.

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5):** much better today than in the past. Schools are aware. But you must teach your child how to protect himself – to ask questions, not share food, etc.

### Discussion on pizza days in schools and milk allergies

**Group discussion including audience ensued about Pizza Days in school and risks to children with milk allergies. Some of the points:**

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5) :** in a large public school, couldn't guarantee that all students' hands and all tables will be washed after.

**TAEG MEMBER 1:** lives in York Region and they have various foods days (pizza, ice cream, buttered popcorn, etc.) that involve the whole school eating dairy. Her child had severe allergic reaction on one of these days. Now, she takes him out of school 5 days a month to keep him safe. Member is having a hard time convincing the principal, etc. that these food days should be stopped. Seems the fundraising & fun aspect are more important than child's health and learning. Suggestions about how to fight this? How to bring about change in policy?

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5) :** must educate them. Bring awareness to the risk it is posing to the child.

**TAEG MEMBER 2:** see discussion taking place on AllergicLiving.com forum about this. It's not just children with food allergies that are impacted by "pizza days" – also diabetics, celiacs, children with religious-imposed food restrictions (e.g. halal, kosher), etc. Fight it on the grounds that there are many children being excluded. There is no educational benefit to these days – there would be no educational loss if they were stopped.

**TAEG MEMBER 3:** many schools depend on money raised by "pizza days" to help fund school programs. Have to show them that there are alternative ways to raise money that do not involve food.

**(paper circulated for members to write down other fundraising ideas, [click here](#))**

**TAEG MEMBER 4:** Contrary to popular belief, *Sabrina's Law* is not just about nut allergies, it is to reduce the risk of anaphylaxis in schools regardless of the trigger. Section 2(2)(1) of *Sabrina's Law* requires school boards to have an anaphylaxis policy that includes "Strategies that reduce the risk of exposure to

anaphylactic causative agents in classrooms and common school areas”. Tell your principal and raise it with the school board that “pizza days” do not “reduce the risk of exposure to anaphylactic causative agents in classrooms and common school areas.” Remind them of their legal obligations to keep anaphylactic children safe.

### **What does “nut free but not nut safe” school mean?**

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5)** : it means that we do not allow anything with nuts on the premises, but we cannot control what people bring, what they ate before coming to school, what people are eating on the playground, etc. We will do our best to enforce this rule. The most important thing a parent can do is to teach their allergic child not to share food and to read ingredients when they’re old enough, not to depend on others to follow the rules.

### **What is appropriate age to start wearing Epipen?**

**TEENAGE GIRL WITH ALLERGIES:** I’m wearing mine now. Started wearing it in grade 2.

**PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:** Would recommend having kids start wearing them as young as possible. In JK, gave my daughter’s Epipen to the teacher. At the end of the school year, she asked for it back, but the teacher couldn’t find it. Parent of allergic teenage girl panellist was horrified to think what would have happened if her daughter had had an allergic reaction.

### **Are all principals as well trained & informed as you both?**

(audience answer – No, they are the gold standard)

### **When should a parent contact the school about enrolling a child with food allergies?**

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5)** : usually registration happens in February, so let them know when you register. Touch base again in late June; by this time the class placements will be done and you can find out who the teacher(s) will be. Meet again with the principal and teacher at the end of the summer to refresh their minds about the allergies and to discuss how best to keep your child safe.

### **Question for teen panel member: What is the social impact of having food allergies? Have you ever been bullied as a result of your food allergies?**

**TEENAGE GIRL WITH ALLERGIES:** Never been bullied. When she was younger, she liked it when her mom came to all of the “food events”, but as she got older, she would sometimes be embarrassed by her mother’s presence. There is one particular event that they have every year which involves the whole school eating a traditional meal together. By grade 3, she knew enough (and the staff had enough experience) to handle the meal without exposing her to her allergens, but she didn’t have the conversation with her mother about not needing her there until grade 5. Also at birthday parties – when she was little, she wanted her parents there, but it became embarrassing as she got older.

**PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:** agreed. My daughter was able to manage “food” situations on her own before I stopped attending parties to supervise her. I should have let go sooner. The sooner you let the child do their own advocating, the better it is for them in the long run. They have to learn how to take care of themselves b/c parents will not always be with them.

### **Question from member on supervision of snacks and lunches at public school**

**Member thought that teachers were the ones who supervised lunchtime. Member was shocked to discover that it is actually Grade 3 students who are supervising the JK/ SK kids at lunch time. How does school board policy allow this? Why bother do allergy training with teachers if they are not present at the most dangerous time? What about other safety concerns – like choking, seizures, accidents, etc. – how is an 8 year old able to handle this?**

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5) :** At her school they organize the day differently: there are snack stations where children can get snacks on their own before or after recess, so the teacher is there.

As for the lunchroom supervisors: This is a funding issue. There is 1 lunchroom supervisor for every 100 students. They are unionized, and hard to replace if needed. At her school, they have 5 older students PLUS the 2 adults supervising.

**(Member recounted pulling her child out of school as a result of the lack of adult supervision at lunchtime. She would call every morning and ask “is it safe for my child to come to school today?”, and if they didn’t have adult lunch supervisors, she kept the child home. They child missed 5 days of school as a result.)**

### **To panel: Closing remarks to leave with our members?**

**PRINCIPAL, MONTESSORI SCHOOL (JK – GRADE 3):** Keep doing what you are doing. You have a right to a safe education for your child. If your child is not safe, look for somewhere else to school your child or initiate the change you need at your school.

**PARENT OF ALLERGIC TEENAGE GIRL PANELLIST:** It may seem overwhelming at times, but it gets easier. Allergy management becomes part of your everyday life & routine. Don’t be discouraged.

**TEENAGE GIRL WITH ALLERGIES:** make sure your kids always wear their Epipen, then they don’t have to think about it – it’s just part of getting dressed. She only thinks about her allergies when she is confronted by food, but knows she can read labels. She knows that she can always call her mom’s cell phone if she has any questions. Has her parents’ cell phone numbers in her Epipen pouch in case of emergency. Also check out [www.whyriskit.ca](http://www.whyriskit.ca)

**PARENT OF AN ALLERGIC TEENAGE BOY:** It’s not just the everyday school you have to worry about. Think about other activities your child participates in. Take what you’ve learned by dealing with schools and apply it to those other activities. For example, the Sunday school her sons went to regularly served food. She decided to teach Sunday school so she could bring the snacks and make sure they were safe.

**PRINCIPAL, PUBLIC SCHOOL (JK-GRADE 5)** : I want to thank all of you parents for your efforts. You are making the difference and bringing about changes that will keep all children safe. I learn a lot from the parents I meet and it helps me to do my job better. As a result of talking with you tonight, I think I am going to teach the older children at my school how to use an EpiPen.

**Sarah thanked all panel participants & members for attending.**

**NEXT MEETING: NOVEMBER 20<sup>th</sup>** – free session hosted by Anaphylaxis Canada; “Ask the Allergist”  
more info on [www.taeg.ca](http://www.taeg.ca)

### **Fund Raising Alternatives for Pizza Days**

- Gift card sales
- Magazine sales
- Scholastic book club
- Read-a-thon
- Pick a staff – donations “shave a head”
- Dance-a-thon (i.e. similar to Spooktacular event hosted by Anaphylaxis Canada)
- Run-a-thon
- Skip-a-thon
- Skate-a-thon
- Movie Night at the school or at Cineplex (proceeds go to the school)
- Asking for a onetime family donation at the beginning of the year (note: may not be possible, depends on school board policy)
- String dolls
- Have the school charge \$25 per table and set up family yard sale tables in school yard or gym. Table charges (and possibly all proceeds) go to the school
- Sell t-shirts, hoodies, caps with school logo – school “spiritwear”
- Book sale
- Flowers sale
- Silent auction i.e. at school fair